

**Yorkshire and the Humber Kidney Care
Home Therapies Forum**

Tuesday 22nd September 2015

1300-1700

The Strayside Education and Clinical Skills Centre, Harrogate

Notes

1. Introduction and Welcome

A welcome and introduction were conducted by Dr Laboi and Dr Dave Border, Consultant Nephrologists, at York Teaching Hospitals NHS Foundation Trust.

Dr Laboi thanked everyone for attending the forum and highlighted that there was a good skill mix at the forum. Dr Laboi gave special thanks to all speakers and those who had assisted in the organisation of the forum.

Dr Laboi reminded everyone to complete the evaluation forms and advised that presentations were available on request via email to sarah.boul@nhs.net.

2. Patient Experience of the Renal Exercise Group

Chris Geary, Patient

Chris underwent a double transplant 18months ago. A year after surgery she joined an exercise group where she met other transplant patients, dialysis and patients with Chronic Kidney Disease. Attendance at the group is for 10 weeks after which patients are encouraged to continue exercising.

Q: Dr Border asked if Vicky, the physiotherapist who ran the exercise groups, took any body measurements before the exercise regime began.

A: Not on this occasion because Chris missed the first class but other attendees did undergo measurements. Chris was measured around her arms later. Overall Chris felt that she improved.

Comment by Dr Dave Border-

By carrying out these exercises, they found there was an increase in muscle strength which helps toward the rate of recovery and falls etc. The service was originally funded by a grant but the team were able to evidence the benefits and it is now funded by the Trust.

Q: Can you carry on doing exercises – is there anywhere to go once these groups are finished?

A: Yes, there is the local gym or can do these exercises at home with a chair and some weights.

3. Measuring Patient Experience

Claire Reid, Renal Registrar, York Teaching Hospitals NHS Foundation Trust

Conducting research for the last 18 months looking at what is important to patients about their care. Please refer to the presentation which incorporates the results of a survey conducted during the research period.

Questions, Answers and Comments:

Q: Has this research been carried out anywhere else?

A: No-one has asked patients directly what their opinion is, they are using other tools.

Q: Within the free text space at the end of the questionnaire did patients rate their answers to the survey in order of importance?

A: No we are going to collate the answers from the surveys and send them to an independent group to rank.

Q: Did patients rate transport as a high priority?

A: No. It was included but not as the highest priority.

Q: Why did you choose York and Sheffield areas to conduct the research?

A: At the time that the research started these areas had a lot of patients undertaking shared haemodialysis care.

Q: Did you ask patients how long they had been on dialysis? Was there any difference in what was important for those who had been on for a long-time compared to newer patients?

A: Yes, but this did not influence the results – it made no difference.

Q: How did you form the focus group?

A: The survey asked patients if they wanted to join a focus group. There were 4 groups held in York and 4 in Sheffield. The groups were split into patients not on shared care, patients undertaking 5 tasks and patients on home haemodialysis. In Sheffield there was also a group of those self-caring.

4. Can we make it easier for independent HD patients to book holidays in Yorkshire?

Renal Administration Team, York Teaching Hospitals NHS Foundation Trust

Dr Laboi gave a presentation on behalf of the team and proposed the development of a web-based booking service to enable patients to book slots in independent self-care units across the region.

Questions, Answers and Comments:

Q: Dr Laboi asked if the Holidaydialysis.com website would be a good idea?

A: Yes

Q: Would you have to book a dialysis slot first or book the hotel/cottage first?

A: In Harrogate, we have enough room at the Self Care Unit to cover our patients; therefore this would not need to be a consideration.

Q: What if there isn't any room in the Harrogate dialysis unit?

A: We are not able to expand the capacity on our site, but we are hoping to have a unit in Selby and York in the near future.

Q: Would you have to check with your consultant prior to booking?

A: Yes this is one of the questions on the holiday dialysis checklist.

Debbie Fortnum stated that Australia use an online booking form for the dialysis Big Red Holiday Bus which operates in New Zealand.

Dr Laboi asked for ideas/comments on the self-care units to be submitted directly to him.

5. Learning Lessons from Australia: How do we promote and sustain HHD uptake?

Debbie Fortnum, National Clinical Programmes Manager, Kidney Health, Australia

Please refer to the slide presentation. Debbie also shared a number of documents with the group which are available on the website.

Questions, Answers and Comments:

Q: Has there been an increase in infections whilst using the button-hole method? Why is button-holing becoming unpopular?

A: The research suggests that there is an increase in infection rates due to button holing and have subsequently the majority of units in Australia have stopped using this method even though the patients preferred it. Further research is required to ascertain if there is any difference in the rate of infection when a professional or a patient is carrying out the procedure.

Q: How common is CVCs at home?

A: Less than 10% at home have a tego adapter which stay in place for a week. CVCs usually need a carer to assist with operation of the device.

Comment:

Often follows 12 month cycle whereby rolling infection rates are reduced each time professionals have refresher courses.

Q: What order are options listed in the Australian decision aid – is there a power of persuasion in the literature that may sway patient?

A: Try not to be biased as each centre has its own way of doing things. Options are presented in a grid.

6. Developing a Peer Support Programme

Andy Henwood, Patient, York Teaching Hospitals NHS Foundation Trust

Please refer to the presentation.

Questions, Answers and Comments:

Q: Are the programmes being done mostly in person or through an online forum? Do you think it will be effective for a specific group of patients rather than others?

A: Doing mixture of both and not targeting specific groups.

Q: How many people would you need to cover the peer support roles?

A: It is difficult to know at this stage. Work is ongoing to scope the best model.

Comment:

Peer support – 20% of patients were asked if they would undertake this role. People who have been on dialysis longer stated that they wish they had done peer support earlier and those just starting dialysis like the idea of peer support.

7. Dialysis Illustrated

Maria Sykes, Patient, and Van Nong, Art Development Officer, York Teaching Hospitals NHS Foundation Trust.

Art therapy is currently only specific to the York area.

As well as painting subjects of her own choice, Maria is getting commissions from people, some of them bringing in photos for her to paint from. To date, the sale of these paintings has raised approximately £200. Maria has also written a short story called 'Mum needs a Clean' and BKPA funding has been sought in order to get it published as a book.

Examples of the art work are included in the presentation.

Questions, Answers and Comments:

Q Did you do any painting before?

A: Only at school.

8. Closing Remarks & Next Steps

Dr Paul Laboi & Dr Dave Border, Consultant Nephrologists, York Teaching Hospitals NHS Foundation Trust

Dr Laboi thanked everyone for attending the Forum. Dr Border gave especial thanks to the speakers and to those who assisted in organising the Forum.

Any further comments about the Forum should be given to Rebecca Campbell on 07825 256356 or Rebecca.campbell6@nhs.net .

Copies of the presentations are also available on request from sarah.boul@nhs.net.

9. Tour of Harrogate Self-Care Unit

The meeting ended with an optional tour of the Harrogate Self-Care Unit which was funded by charitable funds, British Kidney Patient Association Funding and contributions from both Harrogate & York Trusts.

The unit currently has two stations and a side room. It is located next to the Harrogate Satellite Dialysis Unit and patients are asked to ring the unit on arrival and departure so that staff are aware of who is using the self-care unit at any time. There is access between the two units so that machines can be moved and staff have access via a side door. However, patients in the self-care unit are expected to be self-caring and should be considered no different to a patient dialysing at home. If a patient is not confident to dialyse in this way, then it may be that the self-care unit is not suitable for them.

The group felt that there would be a benefit to dialysing in the self-care unit at the same time as another patient as there would be company and support, particularly if something went wrong.

There is also a two station self-care area within Selby Hospital and plans to develop a self-care unit in York.

10. Next Meeting

Please note that the next Forum will take place in March 2016 in Doncaster - TBC